
CANCER FACTS

National Cancer Institute • National Institutes of Health

Questions and Answers About DES

1. What is DES?

DES (diethylstilbestrol) is a synthetic form of estrogen, a female hormone. It was prescribed between 1938 and 1971 to help women with certain complications of pregnancy. Use of DES declined in the 1960s after studies showed that it is not effective in preventing pregnancy complications. When given during the first 5 months of a pregnancy, DES can interfere with the development of the reproductive system in a fetus. For this reason, although DES and other estrogens may be prescribed for some medical problems, they are no longer used during pregnancy.

2. What health problems might DES-exposed daughters have?

In 1971, DES was linked to an uncommon cancer (called clear cell adenocarcinoma) in a small number of daughters of women who had used DES during pregnancy. This cancer of the vagina or cervix usually occurs after age 14, with most cases found at age 19 or 20 in DES-exposed daughters. The upper age limit, if any, for DES-exposed daughters to develop this type of cancer is not known, and some cases have been reported in women in their thirties and forties. The overall risk of an exposed daughter to develop this type of cancer is estimated to be approximately 1/1000 (0.1 percent). Although clear cell adenocarcinoma is extremely rare, it is important that DES-exposed daughters continue to have regular physical examinations.

Scientists found a link between DES exposure before birth and an increased risk of developing abnormal cells in the tissue of the cervix and vagina, although the significance of these findings is controversial. Physicians use a number of terms to describe these abnormal cells, including dysplasia, cervical intraepithelial neoplasia (CIN), and squamous intraepithelial lesions (SIL). These abnormal cells resemble cancer cells in appearance; however, they do not invade nearby healthy tissue as cancer cells do. These abnormal cellular changes usually occur between the ages of 25 and 35, but may appear in exposed women of other ages as well. Although this condition is not cancer, it may develop into cancer if left untreated. DES-exposed daughters should have a yearly Pap smear and pelvic exam to check for abnormal cells.

DES-exposed daughters also may have structural changes in the vagina, uterus, or cervix. They also may have irregular menstruation and an increased risk of miscarriage, tubal (ectopic) pregnancy, infertility, and premature delivery.

3. What health problems might DES-exposed sons have?

There is some evidence that DES-exposed sons may have testicular abnormalities, such as undescended testicles or abnormally small testicles. The risk for testicular or prostate cancer is unclear; studies of the association between DES exposure in utero and testicular cancer have produced mixed results. In addition, investigations of abnormalities of the urogenital system among DES-exposed sons have not produced clear answers.

4. What health problems might DES-exposed mothers have?

Women who used DES may have a slightly increased risk of breast cancer. Current research indicates that the risk of breast cancer in DES-exposed mothers is approximately 30 percent higher than the risk for women who have not been exposed to this drug. This risk has been stable over time, and does not seem to increase as the mothers become older. Additional research is needed to clarify this issue and whether DES-exposed mothers are at higher risk for any other types of cancer.

5. How do you know whether you took DES during pregnancy or whether your mother took DES while pregnant with you?

It has been estimated that 5 to 10 million people were exposed to DES during pregnancy. Many of these people are not aware that they were exposed. A woman who was pregnant between 1940 and 1971 and had problems or a history of problems during pregnancy may have been given DES or a similar drug. If you think you or your mother used a hormone such as DES during pregnancy, you could try to contact the attending physician or the hospital where the delivery took place to ask whether there is any record that you or your mother received DES. If any pills were taken during pregnancy, obstetrical records should be checked to determine the name of the drug. Mothers and children have a right to this information.

However, finding medical records after a long period of time may be difficult. If the doctor has retired or died, another doctor may have taken over the practice as well as the records. The county medical society or health department may be able to tell you where the records are. Some pharmacies keep records for a long time. If you know where the prescription was filled, you may be able to get this information. Military medical records are kept for 25 years. In many cases, however, it may be impossible to determine whether DES was used.

6. What should DES-exposed daughters do?

It is important for women who believe they may have been exposed to DES before birth to be aware of the possible health effects of DES and inform their doctor of their exposure. It is important that the physician be familiar with possible problems associated with DES exposure, because some problems, such as clear cell adenocarcinoma, are likely to be found only when the doctor is looking for them. A thorough examination may include the following:

- *Pelvic examination*—A physical examination of the reproductive organs. An examination of the rectum also should be done.
- *Palpation*—As part of a pelvic examination, the doctor feels the vagina, uterus, cervix, and ovaries for any lumps. Often palpation provides the only evidence that an abnormal growth is present.
- *Pap test*—A routine cervical Pap test is not adequate for DES-exposed daughters. The cervical Pap test must be supplemented with a special Pap test of the vagina called a "four-quadrant" Pap test, in which cell samples are taken from all sides of the upper vagina.
- *Iodine staining of the cervix and vagina*—An iodine solution is used to temporarily stain the linings of the cervix and vagina to detect adenosis (a noncancerous but abnormal growth of glandular tissue) or other abnormal tissue.
- *Colposcopy*—In colposcopy, a magnifying instrument is used to view the vagina and cervix. Some doctors do not perform colposcopy routinely. However, if the Pap test result is not normal, it is very important to check for abnormal tissue.
- *Biopsy*—Small samples of any tissue that appear abnormal on colposcopy are removed and examined under a microscope to see whether cancer cells are present.
- *Breast examinations*—Thus far, DES-exposed daughters have not been shown to have a higher risk of breast cancer than unexposed daughters; however, they should follow the routine screening recommendations for their age group.

7. What should DES-exposed mothers do?

A woman who took DES while pregnant (or suspects she may have taken it) should inform her doctor. She should try to learn the dosage, when the medication was started, and how it was used. She also should inform her children who were exposed before birth

so that this information can be included in their medical records. DES-exposed mothers should have regular breast cancer screening and yearly medical checkups that include a pelvic examination and a Pap test.

8. What should DES-exposed sons do?

DES-exposed sons should inform their physician of their exposure and be examined periodically. While the level of risk of developing testicular cancer is unclear among DES-exposed sons, males with undescended testicles or unusually small testicles have an increased risk of developing testicular cancer, whether or not they were exposed to DES.

9. Is it safe for DES-exposed daughters to use oral contraceptives or hormone replacement therapy?

Each woman should discuss this important question with her doctor. Although studies have not shown that the use of birth control pills or hormone replacement therapy are unsafe for DES-exposed daughters, some doctors believe these women should avoid these medications because they contain estrogen. Structural changes in the vagina or cervix should cause no problems with the use of other forms of contraception, such as diaphragms or spermicides.

10. Do DES-exposed daughters have unusual problems in pregnancy?

There is evidence that the risk of tubal (ectopic) pregnancy, miscarriage, and premature delivery is increased for a DES-exposed daughter. Although most DES-exposed daughters do not experience DES-related problems during pregnancy, the doctor should be told of the DES exposure and should monitor the pregnancy closely.

11. What is the focus of current research on DES exposure?

The emphasis of current research is to provide continued followup to all DES-exposed groups as they age, and to identify any cancer or other health risks that may be found in these groups. Researchers continue to study DES-exposed daughters as they move into the menopausal years. The cancer risks for exposed daughters and sons are also being studied to determine if they differ from the unexposed population. In addition, researchers are studying possible health effects on the grandchildren of mothers who were exposed to DES during pregnancy.

12. What kinds of education and outreach efforts are in progress?

The Centers for Disease Control and Prevention (CDC) is developing a DES National Education Campaign (DES NEC) with the assistance of the DES NEC Working Group. The campaign will focus on increasing the awareness of the general public about DES exposure and the need for careful screening and followup. It will also provide primary health care providers with up-to-date information about the health effects of DES and

screening and treatment guidelines for DES-exposed groups. The campaign is currently in the research and planning stages, with plans to release the new materials in late 2001.

13. Where can DES-exposed people get additional information?

Resources for people who were exposed to DES include the following:

Organization:	DES Action USA
Address:	Suite 510 1615 Broadway Oakland, CA 94612
Telephone:	510-465-4011 1-800-DES-9288 (1-800-337-9288)
Fax number:	510-465-4815
E-mail:	desact@well.com
Internet Web site:	http://www.desaction.org

DES Action USA is a consumer group organized by individuals who were exposed to DES. It provides information, referrals, and support for DES-exposed people and health professionals.

Organization:	DES Cancer Network
Address:	Suite 400 514 10th Street, NW. Washington, DC 20004-1403
Telephone:	202-628-6330 1-800-DES-NET4 (1-800-337-6384)
Fax number:	202-628-6217
E-mail:	DESNETWRK@aol.com
Internet Web site:	http://www.descancer.org

The DES Cancer Network is a national organization for DES-exposed women and their family and friends. It offers education, support, and research advocacy, with a special focus on DES cancer issues.

Organization: **The Registry for Research on Hormonal Transplacental Carcinogenesis (Clear Cell Cancer Registry)**
Address: Department of Obstetrics and Gynecology
 The University of Chicago
 5841 South Maryland Avenue, MC 2050
 Chicago, IL 60637
Telephone: 773-702-6671
Fax number: 773-702-0840

E-mail: registry@babies.bsd.uchicago.edu
Internet Web site: http://obgyn.bsd.uchicago.edu/registry.html

The Registry for Research on Hormonal Transplacental Carcinogenesis (also called the Clear Cell Cancer Registry) is a worldwide registry for individuals who developed clear cell adenocarcinoma as a result of exposure to DES. Staff members also answer questions from the public.

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Sources of National Cancer Institute Information

Cancer Information Service

Toll-free: 1-800-4-CANCER (1-800-422-6237)
TTY (for deaf and hard of hearing callers): 1-800-332-8615

NCI Online

Internet

Use <http://cancer.gov> to reach NCI's Web site.

CancerMail Service

To obtain a contents list, send e-mail to cancermail@icicc.nci.nih.gov with the word "help" in the body of the message.

CancerFax® fax on demand service

Dial 301-402-5874 and listen to recorded instructions.

This fact sheet was reviewed on 6/27/00